DOCUMENT RESUME

ED 196 254 EC 131 704

AUTHOR Loop, Bertine; Hitzing, Wade
TITLE Family Resource Services and Support Systems for Families with Handicapped Children.
INSTITUTION Nebraska Univ. Medical Center, Omaha. Meyer Children's Rehabilitation Inst.
SPONS AGENCY Department of Health, Education, and Welfare, Washington, D.C.
PUB DATE Apr 80
CONTRACT 79001; 80001; 780212
GRANT DHEW-54P-71176/07-01; DHEW-54P-71176/07-02
NOTE 56p.; : For related information, see EC 131 701-705.

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS *Community Resources; Community Support; *Delivery Systems; *Disabilities; *Family Programs; History; Models; Policy; Program Development; *Public Agencies; *Respite Care

ABSTRACT

The monograph provides an historical overview of services for families of disabled children and considers strategies for increasing family support. The historical analysis traces factors influencing the lack of priority placed on family services and describes trends in family resource services. Advantages and drawbacks of the continuum and array approaches are considered. The array approach is seen to lead communities toward the development of a variety of services rather than continuums of different, segregated environments. Four critical components of such an array model are delineated: meaningful consumer involvement, generic agency development, legal framework, and training. The effects of the continuum approach on the development of temporary supports and respite care are examined. Recommendations for change are made for the program level as well as for the national policy level. (CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

FAMILY RESOURCE SERVICES AND SUPPORT SYSTEMS FOR FAMILIES WITH HANDICAPPED CHILDREN

ED196254

U.S. DEPARTMENT OF HEALTH
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

April, 1980

Written by Bertine Loop with Wade Hitzing
Meyer Children's Rehabilitation Institute
University of Nebraska Medical Center
Omaha, Nebraska

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

L. Loop

CHSS

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

EC131704

AUTHOR'S NOTE

Portions of the following chapter were taken from documents and materials prepared by projects of the Center for the Development of Community Alternative Service Systems, (CASS), Meyer Children's Rehabilitation Institute, the University of Nebraska Medical Center, Omaha, Nebraska.

These projects and this paper were supported by the following major grants and contracts:

DHEW - #54P-71176/07 - 01, - 02.

Iowa Developmental Disabilities Contract #780212

Iowa Civil Rights Commission, Protection and Advocacy Contract #79001, #80001.

Most importantly, I am grateful to the children, their families and Advocates who have never failed to provide me with their support and encouragement.

Bertine Loop

April, 1980

". . . One of the most basic of all rights is that of children having the right to live with their own families. The importance of living with your own family is well documented . . . and protected by laws and courts throughout the nation.

The protection of this right so well afforded to 'normal children' has not been equally applied . . . Indeed, while Department of Social Service and/or Public Welfare Departments have instituted plans to assist family members in coping with personal life problems and the maintenance of the family unit, professionals in the field of Developmental Disabilities have offered out-of-home alternatives to developmentally disabled family members as the key to maintenance. The apparent rationale for this is the belief that the natural family is seldom if ever capable of providing a habilitative environment and program for their developmentally disabled child and/or that without removal of the child, the family will undergo disintegration.

An underlying assumption of the Community Placement Plan is that wherever possible and appropriate the placement site of <u>choice</u> is in the natural family. Likewise, when support services are required for developmentally disabled persons and/or their families, the intention for provision of these services is that of maintaining the individual in his or her own natural home."

<u>Willowbrook Community Placement Plan</u> (1976)

1. Introduction

Services for children with handicaps have undergone considerable development and expansion within the past ten years.

Generally these developments have focused on programs and services in residential settings, schools and other facilities outside of the family system.

Services that focus on developing resources and supports based on the fundamental role of the family as the core of the delivery system for handicapped children have not received the same priority status or emphasis.

There are many factors that have influenced these developments. This chapter will discuss those factors and describe: the background and trends in family resource services for handicapped children; a model array of family-centered resources and supports; the current status of consumer involvement and temporary systems of family supports; a model for training families to be self-advocates; and national policy recommendations and strategies for change.

2.1 Overview: Historical Perspective of Services for all Families With Children

Families are the most individual and basic component of the community ecological system. Current bureaucratic approaches to developing services have failed to recognize this important characteristic of the family. Despite important evidence and description of the family as an ecological system by Hobbs, the expansion of social institutions has substituted outside services for those formerly provided within the family system. This has resulted in the systematic removal of families' ability to control services they receive.

Previous to the development of social institution models, the family had been viewed as the major system to provide itself with opportunities, access and services (i.e., "resources"). With the increasing overlays of complex and often confusing organizations, and public bureaucracies have displaced many functions of the family. The family system has become increasingly dependent on formal resource structures, such as schools, labor unions, corporations, units of governments and human services agencies. (see Table I, next page).

Another effect of this formal resources network has been the investment of planning and fiscal priorities in inflexible organisational models.

TABLE I. FAMILY RESOURCE SYSTEMS (Adapted from Minehan and Pincus, 1973)

LEVEL/TYPE OF FAMILY RESOURCE SYSTEM	EXAMPLES/RESOURCES OFFERED	POTENTIAL DRAWBACKS AND SHORTCOMINGS
1. NATURAL -nuclear family -extended family	-emotional support, affection -advice, information -counseling, parenting -babysitting, convalescent care -tutoring, instruction -resources location -community manipulation and influence -recreation	1) absence of family supports, helping mechanisms 2) reluctance to use family resources 3) inability of family to meet needs, obtain goals, etc. 4) communication and decision-making barriers 5) value conflicts
2. INFORMAL -friends -neighbors -co-workers, colleagues -bartenders, hairdressers	-emotional support, affection -advice, information -counseling, parenting -babysitting, convalescent care -tutoring, instruction -resources location -community manipulation and influence -recreation	1) absence of access to or rapport with available informal resource person(s) 2) reluctance to use informal resource person(s) 3) inability of informal resource person(s) 4) value conflicts to meet needs, assist in goal attainment, maintain growth, etc. 5) communication and decision barriers
3. FORMAL RESOURCE SYSTEMS -labor unions -consumer organizations -advocacy groups -professional organizations -self-help	-negotiation, lobbying -recreation -individual and group emotional support, mutuality -advice, information -service system influencing -monitoring, direction	1) non-existence of formal groups 2) reluctance to invest in membership of formal group 3) lack of awareness that specific formal groups resources exist 4) absence or inadequate power, influence and ability of such groups to meet members needs, goals, etc. 5) inadequate procedures, communications, decision-making mechanisms
4. SOCIETAL RESOURCE SYSTEMS -libraries, schools -hospitals, institutions -voluntary service agencies -legal services -places of employment -social security programs -human service systems	-regulations/policies -medical/health care -brokerage/community resources -monolithic service systems -foster care, respite assistance -public defenders, paraprofessionals, ombudspersons	1) non-existent or inadequate services level 2) geographical, psychological or cultural barriers and restriction to access 3) lack of awareness or how to use system 4) existence and operation of system creates new problems or aggravates old ones 5) use of more than one resource systems may result in cross-purposes, trapping family in conflicting demands and contradictory messages 6) internal organization barriers to effectiveness.

In the broad area of services for children, traditional community agencies serving children have not included priority planning for handicapped children. Although the "New Federalism" policies of the 1960's supposedly designed new and expanded services for children, the resulting service "system" outcome was characterized by fragmentation, competition and duplication from the federal level to the local delivery of services. This situation continues today despite current federal policy goals that stress intergovernmental cooperation, accountability and cost-efficiency (Comptroller General of the United States, 1977).

Each major federal program has specialized concerns, coveted models and elitist technology. This territoriality and bureau isolation makes it difficult, if not impossible to translate policy rhetoric into services based on the basic right of families to be the core component and ultimate controllers of their future community.

Today all parents are, in reality, forced into new roles as advocates, mediators and brokers. Our current human service systems and social institution have not, in fact, developed community resource networks that support the integrity and natural enviroment of the family.

Current funding restrictions in all areas of human services programs will probably continue and have life-long negative effects on handicapped children and their families.

Critical national reports from responsible groups concerned with the welfare of all the children in the United States Have repeatedly identified major factors in national public policty that cause this isolation and life-long dependency of thousands of families with handicapped children.

2.2. Overview: Historical Perspective of Development of Integrated Community Services for Handicapped Children and Relationship to Policies for All Families.

The development of community alternatives to institutionalization for handicapped children has been a major thrust of the deinstitutionalization movement in the community setting. In terms of regulatory interpretation and funding, however, community alternatives receive less than 10% of the funds available for deinstitutionlization (GAO, 1977, 1980). Further, within the community alternatives the majority of community residential services established have been for adults rather than children (Morrell, 1979).

Prevention of institutionalization through services that focus on supporting the family in the natural home environment have finished last when compared to the other thrusts of deinstitutionalization. Financial supports for home-based services, for example, currently receive less than 1% of the total federal expenditures in the area of health and social services.

Recently, community programs and planners are increasingly aware of the limitations to the current approaches for developing services for handicapped children. Agencies discovered that the financial investment necessary for maintaining a handicapped child in a residential program created a disproportionate drain on agency budgets. Further, studies and reports consistently documented the negative effects on family relationships caused by focusing on services offered outside of the family system.

Further, the limited family support services that have been developed have already demonstrated that the costs of community services can be considerably reduced (Gary W. and the United States v. Stewart, United States Department of Justice, 1975).

P.L. 94-142 placed responsibility for the education of handicapped children with local school districts. In many locations, this meant that children who had been previously institutionalized could return home and other children were not forced to leave home to obtain an education.

Across the United States, parents of handicapped children have become organized and actively involved in developing resources and services for their families. Usually, they identify family resources and supports as the top program priority as opposed to the low financial priority of planners and legislators.

At the same time, systematic application of the principles of normalization and developmental model have been a major influence in the broad acceptance of community-based programs (in places where they are adequately funded and supported).

Nevertheless, in terms of total services, family resource services for handicapped children have still not received the same attention.

Family-centered services have lagged seriously behind educational and residential programs for all children in the United States. Despite professional rhetoric and policies, meaningful family-centered resources and services have been compromised and diffused to fit institutional structures that are, by design and service approach, opposed to the very premise that the home environments

of families are the preferred setting for children to grow and thrive in.

Schneiderman (1979) identified several major factors that contribute to this paradox between policy and practice. These factors include:

1) conflicting and confusing definitions fo the "family";
2) individual vs. group value orientation and attitudes toward social responsibility;
3) historic public policy attitude of substituting care from alternative social institutions rather than supporting family resource systems;
4) viewing the family as responsible and liable for problems and changes rather than restructuring the service system.

In the past, the failures of service systems to develop resources and supports for families had little to do with the families' needs and abilities. Too often, agencies have presumed to know the resources and needs of families Lack of involvement by the families was interpreted to mean lack of interest or motivation. Time limitations have often resulted in impersonal letters and notices. Even when agencies remembered to involve the consumers, there was minimal preparation, and little resource information given to consumers that could help them to make decisions and gain access to the decision-making. As a result, the service systems were unable to develop and deliver flexible and individualized services that were accountable to the consumers.

The effects of these factors and the resultant conflict of policy and practices has resulted in a linear or continuum approach to services for handicapped children rather than an array of family-centered services that are truly consumer-oriented. In the next section, these two approaches will be discussed and contrasted.

3.1. The Continuum V. the Array Approach to Development of a Community Model of Family-Centered Resource and Support Systems

A. Continuum of Community Enviroments

During recent years, there has been a growing strategy to develop specific types of community programs for handicapped children and their families. These services are usually educational and/or residential alternatives, with very few programs emphasizing in-home services (early intervention and limited parent training projects are major exceptions).

Community residential programs were developed to provide alternatives to large segregated state insitutions. Gradually, there has been a movement towards utilization of smaller nursing homes and large group home facilities. This is substituting one form of institution for another. The continued abusive conditions in nursing homes and institutions have not prevented a major proportiion of states from utilizing these alternatives, despite the overwhelming evidence for the support of natural home environments (GAO, 1980).

Community residential programs were originally intended to prepare handicapped children for return to these natural homes (or similar natural environments.). However, both families and

and professionals often came to view out-of-home community residential programs as permanent.

Because of this lack of movement through the community residential system, many service providers and planners forcused primarily on expanding out-of-home residential settings along a continuum (Skarnulis, 1979).

Out-of-home residential services, especially for children, are clearly more restrictive and less normalizing than developing the resources and supports a family identifies as needed to prevent such fractures of the family system.

This type of continuum approach has resulted in a rigid relationship between policy and program development that is also used to develop educational services for handicapped children.

In 1975, civil liberties litigation regarding the right of handicapped children to free, appropriate public education resulted in broad policy reform and legislation (P.L. 94-142).

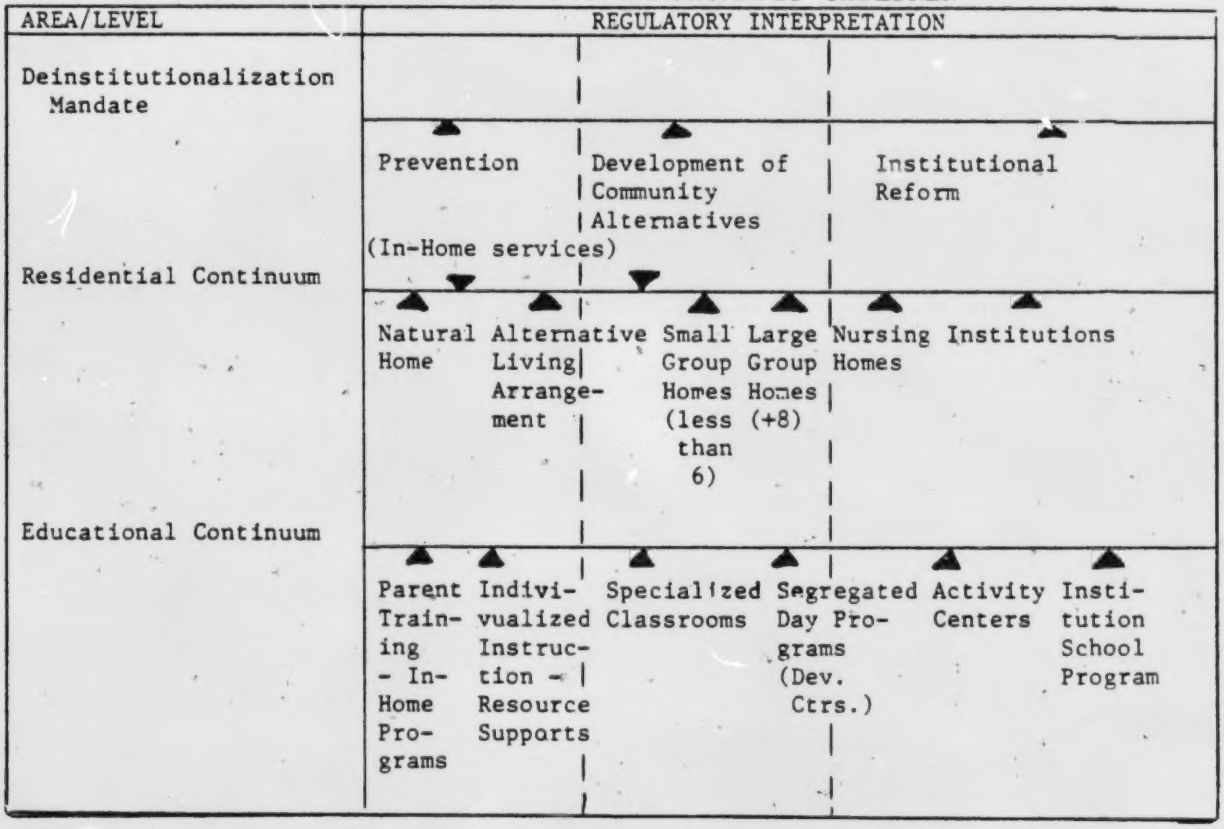
Public Law 94-142, has regulatory mechanisms to protect and ensure the rights of children primarily through individualized planning ("IEP's") developed by a team that should include the child and parents as equal members. Local and state education programs implementing the mandate of P.L. 94-142 have often not viewed the handicapped child and his/her parents as consumers with specific legal rights (McLoughlin, etal, 1978).

The process of negotiating individual education plans was "supposed" to be based on objective analysis of a child's resources as well as his or her needs. The IEP process is currently controlled by educational systems instead of through

a shared joint responsibility with families. As a result, the IEP process supports an education system that continues to fit the consumers into a continuum. Handicapped children themselves continue to be categorized by different facility settings and diagnostic labels (Hobbs, 1976).

This continuum approach to developing both residential and educational systems in communities has paralleled the funding priorities of deinstitutionalization. Although these relationships are sometimes contradictory and complex, the current continuum approach to the community development of services for handicapped children can be illustrated as follows -

RELATIONSHIP OF DEINSTITUTIONALIZATION TO THE CONTINUUM OF COMMUNITY SERVICES FOR HANDICAPPED CHILDREN



It becomes obvious that these funding patterns have financially strengthened the continuum approach, <u>without</u> supporting family-centered services.

It is, therefore, important to closely analyse the implications of basing a service system on a continuum of different residential and educational environments. This continuum, which is so widely accepted, has evolved, in part, because of a national commitment to develop less restrictive alternatives to institutions. Alternatives that are based on more conscious, positive belief systems than have previously existed. In general, if this continuum is compared to what previously existed, when there were few if any alternatives to the institution, it is easy to agree that progress has been made. We have recognized that disabled citizens have a right to much less restrictive living conditions.

For example, it is true that having your needs met by living in a group home in the community is better than having to live in a large segregated institution. Such an alternative is a less restrictive environment. It tends to be more integrative and consistent with the developmental model.

There are, then, several positive characteristics to a continuum of environments:

1. The continuum of environments could be so comprehensive that there are no "gaps" in the community service system.

Each of these environments is said to have "a place" on the continuum. Any state or community that has a wide enough range of these environments can be assured that all of its disabled citizens have an environment which is "matched" to their current functioning level.

2. It allows the client to move through the system as he/she grows and develops. Initially a client is placed in an environment which "matches" or is suitable to his/her current functioning level. As clients progress and gain new skills, they can move or "graduate" to a less restrictive setting.

Without a continuum of environments, this upward movement would not be facilitated.

3. A continuum is more cost effective. Proponents of the continuum argue that a continuum of environments is more cost effective than a service system which relies largely on the institutional model. Those clients who have shown sufficient progress can move from the institution to less costly settings such as group homes, clustered apartments, or independent living situations (Hitzing & McGee, 1976).

The negative implications of the continuum are largely a result of the following basic misconception:

> A handicapped child must have his or her needs met by placement in a specific, usually "special," environment rather than by being provided an appropriate array of services that involves parents and family as the core of the delivery system.

It is true that there have been many positive trends over the last decade: the re-establishment of the constitutional rights of all disabled citizens; the creation of more innovative community service alternatives; a ten percent decrease in the institutional population; and the vitalization of a national consumer advocacy movement.

However, there are also some dangerous trends within the continuum approach which are due to the fundamental misconception cited above:

1. Different groups need different environments - A continuum of environments is based on the belief that different groups or types of disabled citizens require different kinds of environments. We frequently hear that the "new role" of the institution is to be a state resource center, a setting where the multi-handicapped child or adult should live. By developing

a role as the primary service setting for persons with severe disabilities, institutions are attempting to ensure their continued existence and future growth.

Group homes are emerging as "the" residential environment for moderately and severely disabled children because many people assume they cannot be served in more independent or integrative settings.

Nursing homes, or "crib" homes, have become the basic residential solution for children with special medical needs.

An indication of this trend is that it is now common to read of planning procedures which attach various levels of disabilities to different degrees or types of restrictive environments. This approach results in such statements as:

> "based on our current population of "x" number of severely handicapped individuals, we will need to develop "y" number of group homes."

2. Disabled persons must "earn" their way through the system.

A major danger inherent in the concept of a continuum of different environments is that it tends to place the major burden of integration on the disabled person, rather than on the system. For example, it is common to presume that a severely disabled child must be institutionalized until he or she is "ready" to move into or "graduate" to a less restrictive community environment. Entrance and exit criteria for the child are usually developed for each of the different environments. A classic example of this negative aspect in education can be seen in the toilet training requirements set for entrance to some programs.

In places where supportive services do exist, there is no reason why even a severely disabled child could not be supported in a family setting. Rather than requiring that the child be ready,the community planners and providers should analyze the needs and resources of the handicapped child and family, and then mobilize all the resources and services necessary to maintain the child in this setting.

3. Cost - A comprehensive continuum of community environments requires a tremendous expenditure of funds in the form of capital construction, major renovation, etc. Many states are investing millions of dollars in institutional construction and renovations. This is often done under the guise of developing "more normalizing" environments within the institutional model (Hitzing & McGee, 1976).

At a community program level, these negative trends have resulted in:

1) systems developing with rigid program limitations that cause duplication, gaps and irresponsible planning.
2) permanent fractures of family systems by out-of-home placements and education in accessibility.
3) isolation of educational and residential services from the community mainstream.
4) financial support of family resource systems on temporary grants because of the long-term financial priorities of institutional and out-of-home alternatives.

5) artificial service needs are created that are based on funding availability rather than being shaped by families' growth and change as developmental/ecological systems.

The ultimate result of a rigid continuum approach is that families with handicapped children are forced to support programs of poor quality. Consumers continue to be uninformed and isolated. The existence of unresponsive and rigid community programs are viewed as preferable to none at all!

Reforming and redirecting the current continuum of community environments to emphasize family resource systems will only occur if fiscal and programmatic priorities are changed.

This would require the development of an alternative community service model that is based on the family as the core of the delivery system. Flexible and individualized programs must be organized into a model array of services. It is this alternative approach, or service array of family resources that will be discussed in the next section.

3.2. Model Array of Family Resource Systems and Supports for Handicapped Children and their Families

The current service continuum of community environments has resulted in only partial integration of handicapped children. This has had continuing institutional funding patterns that create entrenched disincentives to family-centered service systems.

Today, we are a a crossroads in the development of programs to support rather than to supplant the families with handicapped children.

(Sharnulis, 1979). All families are faced with the reality of substituting social institutions for family responsibility that has been lost in the current continuum approach.

The current continuum of residential environments ranges from very restrictive to less restrictive environments, from institutions to individualized placements. In order to move away from reliance on a continuum of different community environments, it will be necessary to develop a broad array of integrative service alternatives.

An array of family resources and supports must developed a network of services to handicapped children and their families. It is necessary to focus on the role of the basic value system of the community in the development of such a array. This focus should lead communities towards the development of arrays of services (not continuums of different, segregated environments) necessary to enable a handicapped child, regardless of the severity of handicap, to remain within his or her family.

Funding priorities and long-term cost benefits must be carefully measured and evaluated in terms of a more comprehensive implementation of the foundation principles of community development to insure the complete recognition of a familiy's roles as consummer and core of the community system.

In brief review, the foundation principles include:

-normalization (age and culture - appropriateness);

-developmental model (individualization and integration); and

-human and legal rights (least restrictive alternative, maximum growth environments).

Application of the foundation principles in the development of a systematic array of services and resources for families with handicapped children must include several critical elements to insure recognition of family roles. Four of the critical components or cornerstones of such a community array of services can be characterized as follows:

CORNERSTONE/COMPONENT	EXAMPLES OF APPLICATION
1. Meaningful consumer involvement	· consumer coalitions · monitoring teams · consumer councils · parent support groups · personal self-advocacy
2. Generic agency development	· community orientation and education · traditional agency re-direction (eg, foster care and adoption) · generic development and sponsorship of specialized programs (eg, toybraries and regional resource libraries, homemaker-home health aid programs, Cooperative Extension Agents)

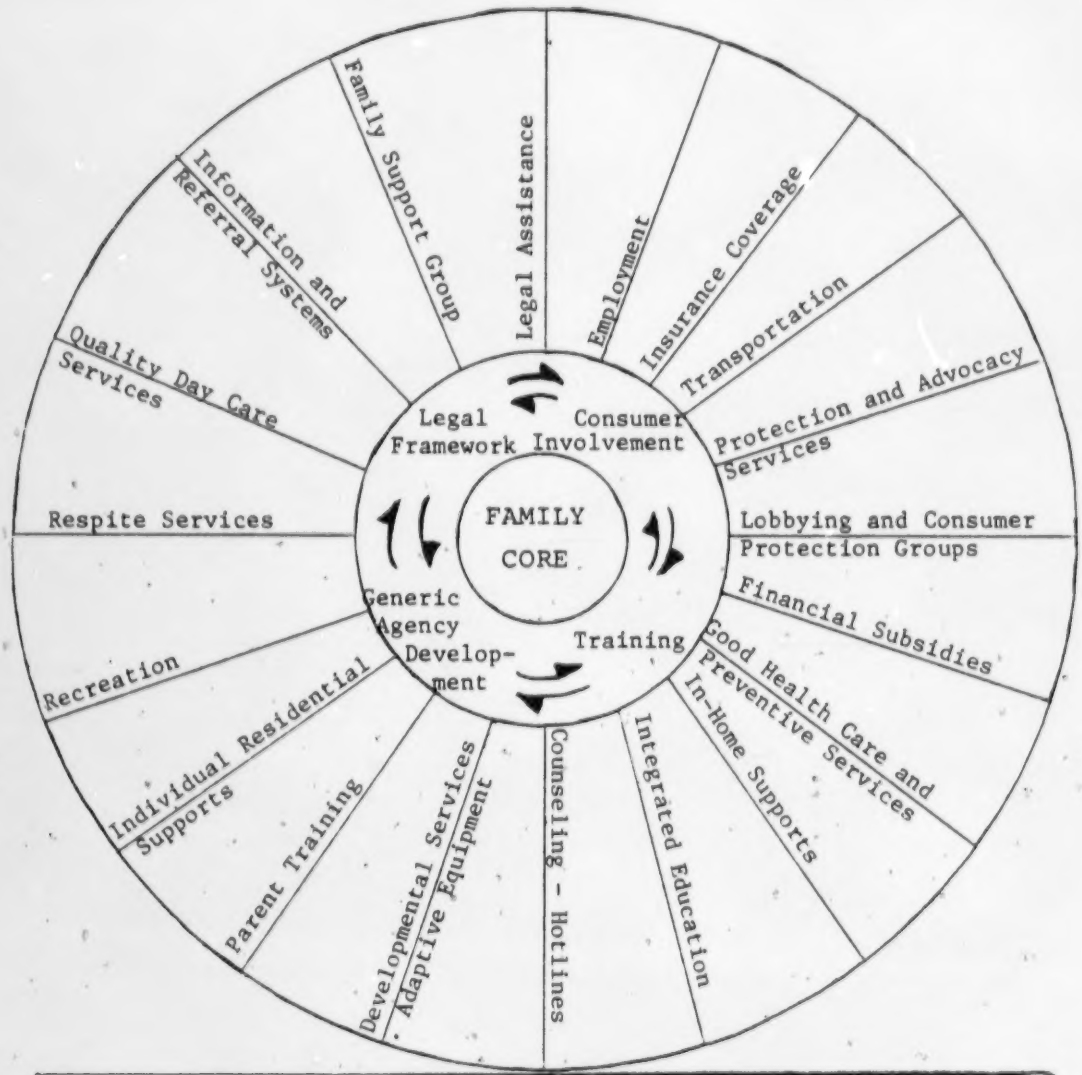
3. Legal Framework	· legislation and financing · funding and regulatory mechanisms · systematic insurance and administrative procedures · standards and accreditation
4. Training	· formal personnel preparation and orientation · specialized skill training · community education and information programs · parent and sibling training

If a community does not include these four critical components or cornerstones when developing a service array, the service program developed will likely not survive the perenniel funding issues or resolve typical programmatic barriers (CASS, 1979).

Community programs that are based on array of services approach will have the following general characteristics:

1. integration into community mainstream
2. provided in-home as well as out-of-home
3. planned as well as crisis-oriented
4. part of a comprehensive community service network
5. short-term as well as long-term
6. individualized and responsive to changing needs and resources of the family or family member (CASS, 1976).

The array of community resources and support services for handicapped children and their families can be illustrated as follows:



MODEL ARRAY OF FAMILY RESOURCE SYSTEMS AND SUPPORT SERVICES FOR HANDICAPPED CHILDREN AND THEIR FAMILIES

Actual descriptions, profiles and characteristics of this model within a specific community setting depends on a number of additional local variables that can be categorized as follows:

a) value premises and community attitudes;

b) community program and agency management models;

c) availability and accessibility of potential resources;

d) regional economic, political and financial characteristics (demographics);

e) cultural variables;

f) state funding priorities and financial patterns of support.

In order to individualize this model array of services and supports, a community must first analyze the resources and needs of the handicapped child, his or her family and the community's available resources. This sould be done at two levels: survey of consumers' resources and needs; and, an inventory/review of the community service network. The information can then be incorporated into a planning process with the family to develop the kinds of support services needed. This planning process is not any different than that of an Individual Program Plan or Individual Educational Program.

It can be simply illustrated as follows:

Community Planning Guide for Implementation

of Model Array of Family Resource Services

Step 1 - Mobilization of Planning Team

- provide orientation on background/issues
- clarify purpose
- develop general goals and strategies
- assign tasks for subsequent steps

Step 2 - Identification of Resources and Needs

- community inventory
- consumer survey
- research of issues, programs, etc.

Step 3 - Assessment of Step 2 Information

- list resources and needs (consumer and community)
- present other information
- review background information
- prioritize potential areas of development

Step 4 - Analysis of Step 3

- identification of barriers and obstacles, and other community realities
- list potential resources for barrier removal or minimization
- consensus re: final ranking of development priorities
- selection of priority area and level of intervention

Step 5 - Action and Implementation

- development of implementation strategies (goals objectives, and tasks)
- assignment of tasks
- implementation of plan

Step 6 - Evaluation and Monitoring

Instead of describing the specific components of the family resource service system model array that a community might develop, the following examples illustrate the variety of options that a community might consider:

FAMILY SERVICES NEEDS, POSSIBLE RESPONSES, AND MANAGEMENT MODELS

NEED STATEMENTS	POSSIBLE SERVICE DELIVERY RESOURCES AND RESPONSES	SAMPLE COMMUNITY SERVICES MANAGEMENT MODEL OPTION
1. Parents divorcing - request temporary live-in to clean and babysit with three children, one of whom is deaf and blind.	- Professional homemaker to care for home. - In-home resource to train (teacher) homemaker and assure life-space continuity.	Department of Social Services Visiting Nurse Association Homemakers, Home Health Aid Agency RSVP Program Community Developmentally Disabled Agency Trained sitter
2. Developmentally disabled child returns home in full-body braces from hospital; mother is 7 mos. pregnant, threatened premature delivery. Two other siblings.	- Father and grandparents learn lifting, turning and general care skills. - Skilled homemaker visits regularity in preparation for mothers absence.	Visiting Nurse Association Hospital in-home team Department of Social Services Homemakers Grandparents
3. Parents unable to toilet train 7 year old developmentally disabled child - entrance to special education program requires acquisition of toileting skills.	- In-home trainer - Toileting devices - Parent training - Physical evaluation of child.	Community college Generic Agency Clinic Special-Education Department of school Pilot Parent Community DD Agency
4. Developmentally disabled adolescent with multiple physical handicaps moves in with grandparents while parents on extended trip.	- Environmental design specialist to provide temporary devicing (tub, ramps, etc.) - In-home teacher to provide program continuity and train grandparents - i.e., lifting, carrying, feeding, exercise. - Temporary part-time in-home assistance (e.g., 2 hours/day). - Alternative transportation to day program.	University Engineering Dept. RSVP Carpenter Visiting Nurse Association Homemakers, Inc. Metro transit or cab
5. Elderly parents inquire about estate and will preparation - Expressing extreme concern about future of developmentally disabled adolescent child should they die.	- Provide list of attorneys, insurance agents, or bankers. - Create access to parents who have coped effectively with similar planning.	Local ARC BAR Association Bankers Association Business and Professional Association Pilot Parents Protection and Advocacy Agency Community Office of Aging

FAMILY SERVICES TABLE CONTINUED

6. Developmentally disabled child, extremely hyperkinetic, sleeping in parents room with door barracaded to keep him from wondering. Parents totally exhausted and seeking permanent institution.	- Provide out home short-term, goal specified placement and parent training. - Gradually return child to home as behavior changes and provide for intermittant respite care.	Community mental health agency Local D.D. Service Agency Crisis Services out of home Pilot Parents

(Skarnulis, 1979)

The critical factors in designing an array of family resources services are both the resources and needs of each family. A survey os potential service consumers does not have to be complicated or take a long time. The most important aspect of designing a consumer survey is the inclusion of questions related to family resources as well as questions regarding needs. A simply survey can give planners critical information about service types, fees, and consumer profiles. The following is a sample of questions used in a consumer survey that has been used with over a thousand families across the United States to plan in-home services.

CASS - CONSUMER SURVEY

1. What do you do when you need to leave your son/daughter with someone?

   I leave my son/daughter with/where (relatives, immediate or extended family; neighbors or friends; residential facility; foster care home, board and care home; sitters, if you check sitters, please indicate fee paid; other).

2. I have not left my son/daughter with anyone because:

   I have not found anyone willing to provide needed services; I have not felt the available persons were qualified; my son/daughter has too many problems; my husband/wife will not allow it; I cannot afford available services; other.

3. Have you ever used any relief care or home support services available through local community agencies?

4. In what kind of situation have you used these services? (planned, e.g., for a vacation; weekend off; crisis or emergency; both; other).

5. If the following services were provided, please indicate how you would rate them. (Needed, Not Needed, Uncertain/More Information Needed)

   a. Trained in-home support personnel to provide specific and specialized programs and/or training for my son/daughter.
   b. In-home support training for parent (myself/spouse) and/or other family members.
   c. In-home support personnel to provide sitter care for my son/daughter.
   d. In-home support personnel to provide companionship for my son/daugther.
   e. In-home support person to provide homemaker or home-health aide services.
   f. In-home adaptive equipment or architectural barrier removal, modifications, etc.
   g. Temporary out-of-home sitter care services (less than 24 hours).
   h. Temporary out-of-home companionship for son/daughter.
   i. Temporary out-of-home living arrangement and/or services (less than 14 days).
   j. Temporary out-of-home living arrangement and/or services (15-30 days).
   k. Self-help support group for parents and/or son/daughter (e.g. Pilot Parents, Association for Retarded Citizens, People First, United Cerebral Palsy, National Society for Autistic Children, Epilepsy Foundation of America, etc.).
   l. Family counseling (e.g. ministers, social worker, therapists, mental health clinics, etc.)
   m. Medical/genetic counseling.

6. Would you <u>use</u> these relief care or home support services if they were provided?

7. Considering <u>only</u> the services you checked in Number 5, indicate your ability to pay for them. (Yes, Totally-Yes, To Some Degree - No)

8. How do you feel these services should be paid for? (I should pay for this service; a public agency should pay; I should pay, with some help from a public agency; other).

9. When would you be most likely to use/need respite services? (Evenings; weekends; weekdays; holidays; vacations; summer; other)

10. Approximately how many hours each day would you use/need these services? (Less than 4; 4-9 hours; more than 9)

11. Approximately how many days each month would you use/need these services? (Less than one day; 1-3 days consecutively; 5-7 days consecutively; 7-10 days consecutively; 11-14 days consecutively; more)

12. What are some barriers or obstacles you might encounter in obtaining the services you need? (Money; family schedules; transportation; services needed are <u>not</u> available; no information on services available; lack of confidence in personnel providing services; other; none)

(CASS, 1978)

There must be safeguards and guarantees that the service system will modify programs so that the handicapped child and his or her family can have their needs met in the least restrictive setting possible. Any deviation from this approach must be viewed as a major compromise with more positive solutions timelined for development and implementation. Such compromises should always be looked at as a function of needs or deficits of the system. Compromises should not base on family problems.

Community service systems have not progressed to the point where there is no longer a need for the out-of-home alternatives currently available. Communities have not yet developed the supportive services and resources needed by all handicapped children and their families to live in their natural home environments. If there is to be a significant change in the way that community services for handicapped children and their families, planners and advocates must seriously question the very existence of the agency-centered continuum approach instead, they must demonstrate committment and active support of the development of the family-centered array of family resources and supports.

In the next section, we will discuss how the continuum approach has effected the development of one aspect of systems (temporary supports and respite services) and how this parallels the current status of consumer involvement.

4.0. Current Status of Family Resource Services: The State of the Art in Temporary Family Support Programs and Respite Services.

There is no comprehensive community-based system of family resources and temporary support (respite) services for handicapped children in the United States today.

Approximately 200 different local programs provide some type of temporary family support services across the country. While these programs represent different geographic areas and cultural groups, serious gaps exist in temporary family support services for non-Anglo families with marginal incomes who live in inner city or isolated rural areas.

The current programs are operated by a wide variety of agencies, professionals, parents, volunteers, and coalitions. The programs are administered in a variety of ways. Because of local funding and regulatory patterns, they are usually reflective of other types of programs in the same state. Private non-profit organizations are the most frequent program sponsors.

The staff of the programs are usually high school graduates who have received 16 hours of orientation and training or less. There is a growing trend throughout these programs to utilize community training and certification programs, such as area community colleges and National Red Cross programs. The state of Washington has been a leader in developing competency-based training for in-home staff. Their program provides 40 hours of training as part of its state-wide Home Aid Resource Program.

Fees for the different kinds of services vary according to the communities in which these programs operate. They typically use sliding scales and subsidies based on a family's ability to pay.

The total budgets for these programs are usually smaller than other community-based programs, with total budget averages of less than $20,000 for a fiscal year. For family resource programs that are not facility-based, the budget totals are usually far less. This is consistent with the current status of other individualized community living arrangements across the country, (such as foster care and individualized living arrangements). When compared to fiscal priorities that continue to emphasize large group homes and institutions. (Morrell, 1979).

Despite the current barriers and disincentives to the development of family resource programs, there are, nevertheless, some exciting and promising examples of activities and programs that illustrate positive developments in family resources for handicapped children and their families in communities across the country (also see Report of President's Committee on Mental Retardation, 1979). Here are several examples from our own experiences:

- The state of Washington has a state-wide network of Home Aid Resources that is capable of immediate response to crisis and planned situations for developmentally disable consumers and their families, within their own homes.

- In Utah, a Cooperative Extension Project was funded by the State Legislature to establish a statewide network of Cooperative Extension Agents. They work in the homes of families with handicapped children, providing training, direct services, coordination and resources.
- A parent-to-parent self-help and support group called Pilot Parents works in Nebraska, and other sites across the United States to set up similar consumer support and self-help groups.
- Family Services of Kalamazoo, Michigan, supports a Parent Respite Care Cooperative where parents themselves arrange for and exchange services with each other.
- The Visiting Nurses Association of Dallas, Texas, has a reimbursement program where families hire, supervise, and pay their own in-home support staff.
- Coalitions of consumer groups in Minnesota, Maryland, and California have effectively introduced legislation aimed at funding family support services.
- A specialized home-based project for developmentally disabled consumers and their families in Georgia has been merged with a generic community service agency.

- Coalition, advocacy and active networking in Louisiana has resulted in allocation of over 1/2 million dollars in Title XX money for Respite Services.
- A homemaker agency in New York has started a project of home-based support for families with parents who have multiple sclerosis and their families.
- The Kansas Children's Service League has a cooperative program of temporary family supports in cooperation with a local Association for Retarded Citizens.
- The Respite Program of the San Diego Association for Retarded Citizens provides sitter and companion services for families with handicapped children when they attend conventions and conferences in the San Diego area.
- The Archdiocese of Denver recruits temporary respite homes and providers through parish associations.

At the same time, there are still a significant number of the programs developed that continue to be variations of limited companion services and/or tied to established residential facilities and foster care homes. Some of the recurring problems in this kind of program development and implementation are:

- narrow focus of program area;
- inconsistent service delivery and accessibility to consumers;

- lack of programmatic monitoring by funding agencies, consumers, and the community at large;
- low financial priority placed on non-facility based services;
- absence of community education and generic agency development;
- lack of formalized agency policies and procedures;
- short term funding (usually via grants and contracts) with little or no development of long - range funding strategies.

Finally, the temporary family support programs that have been discontinued or are under-utilized have two common features. The first is financial instability due to short term funding arrangements. The second and most critical factor appears to be that the services designed and delivered were <u>not</u> the services wanted or needed by the families themselves.

5.0. Current Status of Consumer Involvement

Supporting the individualization of resources and returning service control to families is not as easy as continuing to support the current system that substitutes formal social institutions for family responsibility.

Meaningful consumer involvement often requires changes in general agency attitudes and specific program philosophy. It can be interpreted to mean "giving up" the power structure that is currently controlled by various professional and agency boards, task forces, committees and volunteer activities.

Consumer involvement at these levels is not usually viewed as an equal partnership with the human service planners and providers who design and implement the services that the consumers end up receiving.

The Carnegie Council on Children report on the status of families in this country has examined this issue in the broader field of all services for children. Their report, All Our Children, notes "...Traditionally, people who provide services, at least those publicly funded, (including contractors), have had to account to their bosses, not their clients, for how well they are doing their job...a father has very little to say in how his daughter's day-care center is run, even though he may know more about the center's shortcomings and successes than the bureaucrat to whom they are supposedly being reported...".

Examples of this attitude can be seen daily at a variety of levels. Consumers are forced into "slots" and"openings". Individual identity is lost in the jargon that defines families as

"units of service" and refers to parents with phrases like "'Mom feels..'" and "'Dad' seems to think..." while brothers and sisters are referred to as "sibs...".

The current status of consumer involvement in the development and delivery of services to families with handicapped children is consistent with the continuing policies that emphasize models that change the families rather than the community service systems.

During the two year operation of our (CASS) national grant to study respite services for people with developmental disabilities, approximately 500 families were surveyed. Families often mentioned examples such as the following as being directly related to the issues of consumer involvement -

- Parents are restricted to clinic waiting rooms while their children are taken to therapy programs that the parents could and often should participate in.
- Families are denied access to their records and other information related to the treatment of their children.
- Program planning meetings with families are held away from home at times convenient only for staff.
- Families are left to coordinate their own services from multiple sources because agencies refuse to cooperate.

- Multi-handicapped children are placed in residential programs far from their homes because of lack of transportation and in-home support services.
- Agencies refuse to develop individualized residential programs (in-home services, alternative living arrangements and foster homes) because it would threaten existing out-of-home residential programs and potentially result in loss of income due to "unfilled beds".
- Parents are asked to write support letters for proposed projects that they know nothing about.
- Professionals on national boards are reimbursed for travel expenses while parents on the same boards are without child care or financial support for their involvement.

We do not mean to imply that current programs are always inappropriate or intend to neglect consumers. We do, however, mean that the current focus and design of community programs tends to reflect a general trend to depersonalize individuals and to fragment rather than support families.

The current status in funding source inflexibility and the continued support of out-of-home placements emphasizes the critical need for changes in community attitudes and types of service delivery.

6.0. Barriers to Implementation of Model Array of Family Resources and Support System

There are a number of significant barriers to the effective mobilization of resources to meet the needs of handicapped children within their family environment in an integrated community. All of these barriers tend to reinforce the existence of restrictive environments, prohibit integration and create disincentives for family-centered services.

Today, most agencies and community service programs have a considerable investment in facility-based programs that are agency-centered. The agencies need financial reimbursement for services delivered even if they are not appropriate for the consumers in order to cover the cost of facility maintenance and administration.

The result has been an incredibly entrenched bureaucratic system of financial and program disincentives at both state and federal policy levels that channel resources into social institutions that are not supportive of families despite their demonstrated cost-benefit (GAO, 1977, 1980).

There are signs that things are changing. A few states, (notably Arizona, California, Louisiana, Massachusetts, Pennsylvania and Washington) have begun to fund plans aimed at developing a more comprehensive array of services for supporting families of handicapped children. Federal committment and participation from the field of services for handicapped persons, however, has lagged even further behind (GAO, 1977).

Major recommendations for changes in national policy and program strategies must recognize that the development of innovative techniques and new systems of service delivery can never be enough.

1. The federal government, while providing 91 separate programs related to retarded citizens, has failed to unify these programs into a force that creates quality programs. Often one federal thrust diminishes the impact of another. For example, Title XIX monies have been used to support institutions while at the same time Title XX monies tend to support return to community life.
2. State and local elected officials are often caught in the middle of conflicts between various self-interest groups. There are powerful groups which lobby for the interests of separate programs, programs which often have conflicts of interest.
3. Very few "hard" facts are known about either the costs or benefits of family-centered services. Cost figures are generally so vague that they have little impact on decision makers. Little has been done to identify costs on a per person, per family, per service basis.
4. Quite often consumer advocacy groups are divided in their efforts. For example, in one state the state association for retarded citizens is currently supporting a massive construction plan for the state's institutional system while a number of other local associations are planning to return all their currently institutionalized citizens to their home communities.

5. There has been little systematization of the major factors which make up a comprehensive integrative community service system. The typical community service program with its group homes, and developmental centers does not represent a comprehensive, continuous service delivery system. Service alternatives have often emerged in a haphazard fashion rather than a step by step, planned effort to develop integrative alternatives.

6. As stated before the major barrier to development of quality family resource programs lies in our conceptual approach to program development. It seems that some people literally cannot conceive of severely, multi-handicapped children living, working, going to school in normal settings.

   Now there is a more difficult and in a sense more important challenge. We must convince parents, advocates, and professionals that handicapped children have a basic right to the opportunity for full involvement in their community. It is not a question of whether the approach will be successful. We must make it work, it must be successful.

7. Even in those communities where services are beginning to focus on supporting the person in the natural environment, little is known about managing such a dispersed service system and maintaining quality of services. For example, a community which plans to integrate all disabled citizens is hard pressed to develop an effective management system to control such a dispersed service system. What population base is necessary to support such a system? Who monitors quality? How can the different federal, state and local funding sources be combined to provide a solid, enduring funding base which will be necessary for continued, (Hitzing and McGee, CASS, 1977).

7.0. Recommendations for Change:

A. Program Level: A Model for Training Families to be Consumer Advocates

According to one advocate with a handicapped daughter "....the informed parent is the effective parent...."

Changing from the role of object (passive recipient) to controller and full participant requires a mobilization of community resources and redirection of financial support for all families.

Returning control to families and recognizing the change in their roles as consumers has many benefits besides just that of cost benefit. This approach and redirection can:

- increase the likelihood of program continuity throughout the different environments that a child lives in each day.
- create opportunities for families to learn to effectively control their own home environment as well as the general community.
- result in the equal participation and investment of both families and service agencies through a cooperative network of community services with innovative techniques that are both flexible and accountable.

Effective consumer control is based on recognition and acceptance of the family as a responsible system with many components within a consumer role. Although the characteristics of the components of the family's role as a consumer may and should differ in emphasis and importance for a family at any point in time, they can generally be described as follows:

(1) trainer/teacher of specific intervention techniques

(2) monitor of service and program accountability

(3) service broker and controller

(4) self-advocate for themselves and other family members

(5) program monitor and reporter of provider competence quality

(6) parenting model for professionals and other parents

(7) community educator

(8) program/systems advocate for agency direction and legislative development

(9) community developer and neighborhood organizer.

There are many strategies and techniques that agencies and professionals could use to train families to be effective consumer advocates.

(1) organize, support and advocate for development of parent organizations and natural helping networks that provide resources, information, supports and self-help groups. This strategy has already been successful with families with histories of child abuse, parents of handicapped children, family health cooperatives, and community services for older people.

(2) design and implement programs of preparation and training for parents and family members that include functional intervention techniques and self-reporting systems.

(3) develop and implement programs that include techniques to train families to monitor services and analyze their community support system (using inventories, access checklists, service systems evaluation tools, etc.).

(4) support and lobby for legislation and funding that emphasize the development of concrete/basic home-based supports (homemakers, sitters, equipment, repair services, etc.) as well as intensive social and educational in-home programs.

(5) develop checklists and other measures for evaluating competencies, performance and accountability.

(6) design and implement reporting and feedback systems for inter-agency communication.

(7) assist the implementation of consumers councils to monitor community service programs and oversee community planning.

This type of model for a coordinated consumer-training program has not yet been organized or implemented in the field of services for handicapped persons. It could be part of a broader consumer program, such as the National Coalition of Neighborhoods, Common Cause, or even the Gray Panthers. Nevertheless, it cannot be successful without the support of broad national policy reforms and the implementation of new strategies to support all families, including those families of children with handicaps.

Fragmentation and confusion of federal intent has resulted in policies and procedures that continue to look better in writing than in actual practices and service delivery. The Reports of the National Children's Defense Fund (1976), Carnegie Foundation (1977) and the National Commission on Mental Health (1978) have documented similar barriers to family supports. Both have called for a national committment to federal programs that support community systems where families (natural or otherwise) are the central core of service planning as well as deliver.

Development of such federal programs would likely involve the restructuring, redefinition and ultimate reform of existing federal programs. This would require drastic changes in the focus of the existing policies, regulations and funding strategies of the current federal deinstitutionalization mandate.

This new federal committment must be based on the basic assumption that all handicapped persons, regardless of age, can live and be served within integrated community settings. Programmatic interpretation of this committment should result in comprehensive development of flexible community-based family resource services for all handicapped children and the prevention of institutionalization or permanent displacement outside of a

family environment. It can no longer be assumed that a handicapped child needs institutional or congregate placement simply because he or she cannot be maintained in the natural family unit.

Divorce, death, and medical crisis are all examples of situations that may result in a necessity for out-of-home services. Innovative adoption and foster-care programs have clearly demonstrated the viability of a "family" oriented approach and the important role of a stable natural home environment for the well-being of children (Child Welfare League of America, 1979). Foster and adoptive homes also need similar supports and family resources. While cost benefit comparisons with institutional placements can sometimes (but not always) be made, the major issue is the right of handicapped children to grow up in families that have the resources and supports to provide for their needs.

The issues involved in developing family resource policies and strategies for handicapped children are not different than those needed to support all of the children of the United States. According to the Carnegie Foundation (1977), changes in national policies and services to families must be based on a new set of principles that will include standards to measure:

- universal access
- racial and economic integration
- convenience and coordination

- parent participation
- utilization of paraprofessionals and volunteers
- emphasis on prevention and family integrity.

In summary, the Carnegie Report described a national program of comprehensive policy to support children and their families that include the following service areas:

1) jobs and flexible working conditions for parents
2) guaranteed minimum income level for all families
3) integrated networks of family services that stress prevention and are monitored by local consumer councils
4) national health insurance and networks of community health systems based on existing health agencies
5) improved legal services and protection

The Report recommended that these activities be systematically included at several levels:

a) within federal policy (where intent is translated public into regulatory financial priorities) that are intepreted into
b) local services for consumers.

Finally, the Carnegie Report noted that a national program to support children and their families would require a cooperative network of families and their community support system.

7.0. Recommendations for Change:

B. National Policy and Strategies

The growth and development of community-based family resource systems and support services have been hampered by service barriers or obstacles at both state and national levels that are characterized by:

- agency isolation which results in the development of programs that have no access to information from other local, regional and federal levels;
- absence of federal and state committment to planning community-based service systems that have respite services and family resources as a primary priority.

Current community-based service programs are not in a position to provide adequate resources for providing needed leadership because:

- systems are narrow rather than comprehensive in scope;
- budget and staff limitations limit the resources available to programs;
- programs are localized and often unknown to persons in need of information;
- there are no regional, state, or national mechanisms for accessing or disseminating information regarding model family resource programs, management approaches, funding strategies, etc.

The following is a set of recommendations for a National Strategy to support families with handicapped children that is consistent with those of the Carnegie Foundation. They are primarily based on issues identified by participants at the Frist National Conference on Temporary Family Supports and Respite Service Systems for developmentally disabled persons and their families (1978). In summary, such a National Strategy would include:

1) identification of a major Federal Bureau that is specifically mandated to support consumer-centered services for Families (Family Resources Bureau) and contains a specialized department to deal with the issues concerning handicapped children and their families.
2) formation of a National Coalition for Family Resources with an elected National Board made up of consumers, parents, advocates and other family representatives.
3) introduction of federal and state legislation that supports family subsidy programs where families themselves can financially control services and supports provided (with a major focus on in-home and alternative living arrangements).
4) development of a cooperative political base for mobilizing full-time advocacy efforts for family resource programs within different consumer groups,

federal and state agencies, Congress and other national groups (e.g.s, National Children's Defense Fund, the Carnegie Foundation, etc.)

5) generation of major funding support for national studies that will assess the impact of current federal policies and programs on the development and administration of family resource programs and their relationship to the family environment.

6) establishment of a national clearinghouse of Family Resource Services advised by the Board of the National Coalition that would:

- maintain a communication network;
- develop more effective mechanisms for dissemination of federal and state level information to local grassroots consumer organizations;
- coordinate and participate in regular multi-level conferences, meetings and hearings;
- compile and disseminate annual resource directories of family resources and temporary supports;
- provide/develop a program of technical assistance, resources and training for federal agencies that will sensitize them to the needs of families with specific emphasis on the impact of these services on the family system, (e.g., decreased institutional placements, maintenance of natural family environments, etc.).

7) design and implementation of model Family Ombudsman Projects and Family Advocacy programs at both state and national levels.

8) advocating for the development of federal or state legislation, regulations and voluntary standards for family resource programs and service providers.

Final Implications

Implementation of these national policy recommendations would reflect many of the following policy and implications identified by Hitzing and McGee (CASS, 1977) in an earlier analysis of integrative support services for consumers with developmental disabilities -

1) recognition of full and legal rights through programmatic implementation of the principles of the least restrictive alternative. By focusing on and meeting the needs of the child, the family, or the community in natural environments, the least restrictive alternative will have been attained. The concept of "least restrictive" will cease to be relative and arbitrary. Instead, it will presume the natural home setting to be the least restrictive. The removal of the handicapped child from the natural setting or the placement of an institutionalized person in an artifical life environment will be seen as an abridgement of the person's rights and a major compromise by the service system.

2. The full recognition of the handicapped child as a developmental being. By both physically and socially integrating the handicapped child into natural community environments, a child, despite his/her type or degree of handicap, will be looked upon as a developmental person, capable of growth. Developmental growth will not be seen as requiring a segregated environment. Instead, it will occur with individualized supports and resources in integrated community settings controlled by consumers and their families.

3. The further development of the principle of normalization as supportive of families, cultures and environments. The principle of normalization will be recognized as both a process and an outcome. Over the last decade normalization has helped us focus on "establishing, maintaining or supporting culturally normative behaviors." However, the current approach to developing services have not always used means that are a culturally normative as possible. There will be broad recognition and acceptance of the attitude that persons with disabilities do not have to earn the right to be integrated into the community mainstream or to remain part of his or her family.

4. Supporting, not supplanting the natural home. The first response to serving a handicapped child will not be to assume that outside placement is needed. Instead, agencies and planners will ask "How can we help keep your family intact." Supporting the child in his or her family environment will be accomplished through a wide array of services and creative service options that are flexible and individualized.

5. Integration will be the responsibility of the service system and not the handicapped child and his or her family. If we are dedicated to the support of families with handicappe children, then it will be necessary to understand that integration of the person depends more on the type and quality of the community service system rather than on the person's needs and individual "progress".

6. Current funding patterns which emphasize permanent facilities and long term out of home programs will be reversed. Society cannot afford both a continuum of agency-centered programs (such as state institutions, group homes and nursing homes) and a full array of family resources and support services.

There must also be a basic committment to the fundamental principles of consumerism and family integrity.

It requires more than tokenism and "lip-service." It means developing strategies and activities at both policy and program levels that are aimed at changing the community service delivery system and professional attitudes, as well as providing support through intensive and innovative techniques.

The development of family resource services that are flexible and individualized to meet a family's needs is a long-neglected challenge. Resources for handicapped children and their families must be part of a broader movement to support the well-being and integrity of all children and their families. A national policy to support families, however continues to appear remote in view of current structures and funding patterns.

The most creative service options that will be developed in the meantime will still be those developed in spite of funding limitations by communities that recognize the change is not the family's responsibility but is shared by the systems that are supported by the taxes of parents and the presence of their children in those programs.

REFERENCES

Carnegie Council on Children. All Our Children: The American Family Under Pressure. Kenneth Keniston, ed. Harcourt, Brace, Jovanovich. New York, New York, 1977.

Center for the Development of Community Alternative Service Systems (CASS). Respite Services Community Development Project. Meyer Children's Rehabilitation Institue. University of Nebraska Medical Center, Omaha, Nebraska 1976-1978-1979.

Center for the Development of Community Alternative Service Systems (CASS). A Consumer's Monitoring Guide. Meyer Children's Rehabilitation Institute. University of Nebraska Medical Center. Omaha, Nebraska. 1977

Center for the Development of Community Alternative Service Systems (CASS). The Development of Community Alternative. Meyer Children's Rehabilitation Institute. University of Nebraska Medical Center, Omaha, Nebraska. 1978.

Child Welfare League of America. Children Adrift in Foster Care. Child Welfare League of America. New York, New York 1979.

Comptroller General. How the Federal Developmental Disabilities Programs are Working:Report to the Subcommittee on the Handicapped. General Accounting Office (GAO). United States Government Printing Office. Washington, D. C. 1980

Comptroller General. Returning the Mentally Disabled to the Community: The Government Needs to Do More. General Accounting Office (GAO). United States Government Printing Office. Washington, D. C., 1977.

Hitzing, Wade and McGee, John. Current Residential Services: A Critical Analysis. Center for the Development of Community Alternative Systems (CASS). Meyer Children's Rehabilitation Institute. University of Nebraska Medical Center. Omaha, Nebraska. 1978.

Hobbs, Nicholas. The Futures of Children. Jossey-Bass. San Francisco, California. 1975.

McLoughlin, J. A., Edge, D. and Strenecky, B. Perspective of Parent Involvement in the Diagnosis and Treatment of Learning Disabled Children. Journal of Learning Disabilities, 11, 1978.

Morrell, Bonnie Brown. Deinstitutionalization: Those Left Behind. Social Work. 24 (6), November, 1979.

National Commission on Mental Health. Report to the President. United State Printing Office. Washington, D. C. 1979.

Schneiderman, Leonard. Against the Family. Social Work. 24 (5), September, 1979.

Skarnulis, Ed. Supports Not Supplant the Natural Home:Serving Handicapped Children and Adults. In Home-based Services for Children and Families: Policy, Practice, and Research. Shelia Maybanks and Marvin Bryce, eds. Charles C. Thomas. Springfield, Illinois. 1979.

Taylor, Tawara and Loop, Bertine. Final Report of the First National Conference on Temporary Family Supports for Developmentally Disabled Persons. Meyer Children's Rehabilitation Institute. University of Nebraska Medical Center. Omaha, Nebraska. 1979.